medConfidential
KEEP OUR CONFIDENCE

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Dear Biobank’s current and future leadership,

Hello again.[1]

It was unclear in 2023 whether Biobank checked the details of applicants, and shown in 2024 that Biobank does not check the details provided by applicants.[2] Rory’s public and private comments in response suggest that the only way to convince him that Biobank did what Biobank has said it has done – gave Biobank data to a project run by eugenicists – is for the eugenicists to use the data Biobank gave them for (at best) the purposes of promoting eugenics (or in the case of Biobank’s user[3] itself, possibly actual eugenics); perhaps you’ll offer them a keynote at the Biobank annual research conference.

1. Reflecting the shared culture between Biobank and HDRUK, does Biobank’s current leadership agree with Biobank’s former Chief Scientist at the launch of their HDR/Sudlow Review saying Biobank should be “used as widely as possible” and access should be granted in “days” because Biobank have “one of the best systems” for access? Do those comments accurately reflect Biobank’s practices?

You’ll now be aware from new reporting by The Guardian, or from reading the biobank website, that UK Biobank sent data to an organisation *after* it had been sanctioned.[4] It has already been shown that Biobank does not check addresses, and it is now clear Biobank does not check sanctioned entities.

2. When Biobank says “all researchers are checked against international sanctions lists”, what does that actually mean?

3. What data did Biobank make available to this project?
    a. What data did the users download? (if different)
    b. Did Biobank make available the GP data received ((un)lawfully?) directly from TPP prior to 2018 (for which we understand NHSE is legally responsible)?

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[1] https://medconfidential.org/wp-content/uploads/2023/10/biobank.pdf and https://medconfidential.org/wp-content/uploads/2023/11/biobank-again.pdf and https://medconfidential.org/wp-content/uploads/2024/05/biobank-hostile-states.pdf

[2] Such as your eugenicist users operating from the same front address as anonymous QAnon front companies…

[3] Incorporated in Wyoming where there is no public information on who owns the company for Biobank to have checked in advance of The Guardian’s reporting.

[4] https://www.theguardian.com/technology/2025/apr/15/revealed-chinese-researchers-access-half-a-million-uk-gp-records

4. How much notice did Biobank give BGI that downloads of data would be ending?
    a. Was the notice BGI received any different to that of any other users?

5. Why did Biobank leadership give warnings that Biobank would be restricting downloads before it happened?[5]

medConfidential supports Biobank’s move away from high risk downloads, but any TRE has to be trustworthy and satisfy the spirit and practice of five safes (if that is the model you wish to use). We have seen a letter to Biobank from some of your users suggesting that your RAP is not an effective TRE, saying explicitly:

> “a nefarious user could trivially export data from RAP in several different ways (as the UKB access team have confirmed).”[6]

6. Do Biobank’s stakeholders believe the current RAP is compliant with “safe outputs” expectations for a NHS SDE, or the other tests of a five safes environment?

7. Does Biobank believe that it has an implementation of the five safes model that is robust against the militaries of “hostile states” operating within your RAP as disclosed by the Guardian?

Future pathways forwards for consented and unconsented cohorts[7]

Despite the protestations to others from Biobank’s current leadership, a well run Biobank need not be of concern to medConfidential – medConfidential believes Biobank remains a unique resource that it is vital to manage well to remain usable for research. We hope Biobank’s Board can find a way along the path towards rebuilding confidence, a path previously taken by the Cancer Registry after their single incident with a “causes of cancer” project.

As with the cancer registry, a consensual, safe, and transparent Biobank should receive data as those who chose to participate have agreed; current Biobank (and OFH) leadership appears to be committed and insistent upon lobbying for the most toxic approach possible. NHS England breaking their “pandemic only” promise about GDPPR is toxic to public confidence, and was rejected in 2023 for good reason, yet Biobank seems insistent on ignoring all questions asked since the summer of 2023.

The shared culture of Biobank and HDRUK suggests the creation of the HDRUK-Service in their image may prove unwise. As with the continuing odour of scandal around Biobank, it is a wasted opportunity or change to a new service that could be consensual, safe, and transparent.

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[5]

[6] https://docs.google.com/document/d/1LIUyHEq6_7x1dD8_7Cq936BRVnrcN83iZL0wyijW-eA/edit?tab=t.0

[7] While UK Biobank and HDRUK share a culture, it is unclear whether UK Biobank is actively involved in the impending bait and switch between consented and unconsented cohorts, which is out of scope of this letter.

Biobank's work on Proteomics

It is the position of UKRI and colleagues and the practice of UK research (in the broadest possible sense), that genomic data is highly sensitively identifying of individuals, and that modern science and bioinformatics allows one to map between a proteome and a person's genome,[8] and still continues to publish proteomes openly on the internet,[9] in some cases requiring that proteomes are published online[10].

While it is not for Biobank HQ itself to do research using Biobank, the new proteomics datasets from Biobank may be a unique resource to demonstrate that proteome publishing in 2025 is a risk to those who are donating their proteome to science without being aware that "science" will effectively publish their genome. Such events are now a topic on which some in Biobank have a visceral understanding, and Biobank could choose to work with colleagues on how to get to a better place before legacy practices become a public calamity.

You'll be aware it is far better to prevent disasters than to cleanup after them, and we hope such prevention elsewhere can feed back to Biobank's stalled position on GP data which remains as it was in 2023;[11] the main difference being the number of investigations into Biobank's choices has kept going up matched only by the intransigence of those Biobank allows to speak. Biobank can continue to work against a consensual, safe, and transparent data infrastructure, or it can contribute to enhancing it. At some point, all unsafe practices end, the question is only whether you wish to also pay the cost of delay.

Yours sincerely,

Phil Booth

Phil Booth, medConfidential

Sam Smith, medConfidential

cc Lord Vallance, Prof Sir Chris Whitty, Prof Sudlow, AMRC, NHSE, Wellcome.

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[8] https://www.nature.com/articles/d41586-024-03236-1 Walker, C. R. et al. Cell https://doi.org/10.1016/j.cell.2024.09.012 (2024).

[9] Bandeira N, Deutsch EW, Kohlbacher O, Martens L, Vizcaíno JA. Data Management of Sensitive Human Proteomics Data: Current Practices, Recommendations, and Perspectives for the Future. Mol Cell Proteomics. 2021;20:100071. doi: 10.1016/j.mcpro.2021.100071. Epub 2021 Mar 10. PMID: 33711481; PMCID: PMC8056256. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8056256/

[10] E.g. https://www.ebi.ac.uk/pride/markdownpage/license

[11] Note the stated BMA position which merely asks Biobank to be transparent about the activities about which concerns have been raised. https://www.thetimes.com/uk/healthcare/article/bma-holding-back-research-by-refusing-to-endorse-appeal-for-data-times-health-commission-l3fsq579g